

## **Statement by Jackie Golden,**

Thank you for attending today's forum, and I wish to also thank the Special Committee on Aging for presenting this topic today. The title of today's forum says it all, "Can We Rest in Peace, The Anxiety of the Elderly Parent caring for Baby Boomers with disabilities."

My name is Jackie Golden. I am a Joseph P. Kennedy Fellow honored to be working with the Special Committee on Aging. I am also a Parent of a young man named Joshua Golden. Joshua is 17 and has Angelman's Syndrome, a deletion of chromosome 15. For the Golden Family, this doesn't mean we don't have dreams for our son, nor does it mean we can provide his care alone. We need supports in the way of care, accessible housing, and school programs to make his care complete. We have set up Joshua's supports through the principles of Self-Determination, which you will learn more about from the panelists. Without these supports I know I would not be here.

We are lucky. Our family is receiving supports. But let me tell you, it took a crisis for the support services to begin. We received excessively supports because of our all or nothing support system. The State of Maryland is now using the model of Self-Determination and now not only is Joshua and my family benefitting, but also the State of Maryland, as the services we truly need are cheaper. However, as I said we are lucky. There are hundreds of thousands of families throughout the United States that are still waiting for supports, waiting for their crisis.

As our panel will share, many of Parents are well into their 70's, 80's, and 90's. While preparing for this forum I researched many States, the oldest Parent I found had just turned guardianship of her son over to someone else so she could go into a nursing home. This wonderful mom is 101, her son is 63! This is not uncommon as we will hear today.

Let me review briefly how a parent goes about accessing the supports they need. Parents request supports from their state agencies. Once the request is made they are informed there is a waiting list for services or supports. The supports that families are looking for can take many forms but I can tell you they are only asking for what they need. Family supports or services can mean someone to come in and provide the family with a much needed rest. It could mean some financial support with supplies that are not covered under the families insurance. The families may need a day program for their child so the parent can work, and give their child an activity during the day. It could mean residential services, where the child with a disability can live an independent life.

Many people including staff in the congress think, well if you have a child with a disabilities you automatically receive medicaid, this is far from true. Many families fall through the cracks, and receive nothing as the long waiting lists bear out.

Many families have been on waiting lists most of their child's life and never do receive services. My hope is that today's forum will shed some light to this dark issue and I hope will share some new innovative approaches to a difficult situation.

The Special Committee on Aging is interested in this issue because of the parents of baby boomers with disabilities are living with a dual complexity. Their own failing health and long term care. As well as their Adult child with disabilities future. We would like to explore ways the Federal Government can help solve these problems.